Bureau of Primary Health Care
The People We Serve..The People We Are

Consensus Conference of Health Status Gaps of Low Income and Minority Populations: A Synopsis

DECEMBER 7 - 8, 1995

U.S. Department of Health & Human Services
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DEPARTMENT OF HEALTH & HUMAN SERVICES

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BUREAU OF PRIMARY HEALTH CARE

Health Resources and
Services Administration
Bethesda MD 20814

Dear Colleague:

I am pleased to share with you this Consensus Conference of Health Status Gaps of Low-Income and Minority Populations: A Synopsis. The Conference was sponsored by the Bureau of Primary Health Care (BPHC) in December 1995. One of BPHC's goals is to improve health outcomes and reduce gaps in health status for low-income and minority populations. Our programs address this goal by identifying community-wide health problems; providing outreach, education, and preventive/primary care; and reducing the need for more expensive curative services.

Measurement of our programs' success in meeting our goals must be increasingly stringent in view of the Government Performance Results Act requirements and shrinking resources. Evaluation must be outcome-driven in view of its scientific validity and marketplace competition.

The BPHC convened a meeting of experts to recommend how to proceed in measuring our programs' impacts on these health status gaps. Conference participants included epidemiologists, health services researchers, Federal program officials, representatives of BPHC's programs, and people whose expertise is in one health condition or area. Using a variant of the National Institutes of Health-pioneered consensus-conference format, participants were asked to help us develop a study agenda to measure gaps in health status; suggest how the health-status measures could be used to evaluate our programs; and recommend what measurements and which data sources to use.

We have found their deliberations most helpful and invite you to share a summary of their discussions.

Sincerely yours,

Marilyn H. Gaston, M.D.
Assistant Surgeon General
Director

6351 HKSTT 95-106 (Executive Summary)

Executive Summary

CONSENSUS CONFERENCE ON HEALTH STATUS GAPS OF LOW INCOME AND MINORITY POPULATIONS: EXECUTIVE SUMMARY

December 7-8, 1995

The Bureau of Primary Health Care (BPHC) convened a meeting of experts to recommend how the BPHC can proceed in developing health status measures for evaluating its primary care programs. Conference participants included epidemiologists, health services researchers, federal program officials, representatives of BPHC's programs (e.g., from community health centers), and people whose expertise is in one condition or area.

BPHC's programs have as one of their goals improving health outcomes and reducing gaps in health status for low-income and minority populations. BPHC's programs address this goal by identifying community-wide health problems; providing outreach, education, and preventive/primary care; and reducing the need for more expensive curative services. Measurement of the programs' success in meeting the goal must be increasingly stringent 'in view of the Government Performance and Results Act (GPRA) requirements and shrinking resources, as well as outcome-driven in view of its scientific validity and marketplace competition.

Outcome measurement is one of sii priorities in BPHC's strategic plan. To implement its data and evaluation strategy, BPHC has developed an annual reporting format common to all its programs; conducted a major national survey of programs' users allowing comparisons with the general population; and refocussed its one percent evaluation studies on quantifiable outcomes.

I. THE PURPOSE OF THE CONFERENCE

BPHC convened this conference to discuss potential measures of primary care outcomes using known health-status gaps in conditions either between majority and minority people in the United States or between those of higher- and lower-socio-economic (SES) status. Because the purpose of this meeting was to develop potential measures for assessing BPHC programs at some stage in the condition's progression, primary care must have a significant effect in preventing, treating, controlling, or ameliorating the condition and/or its sequelae. Standards of care must exist before considering a specific condition or disease for inclusion. Using these criteria, the conditions selected for discussion were diabetes; hypertension, cardiovascular, and cerebrovascular conditions; breast, cervical, and prostate cancer; infectious diseases including AIDS, sexually transmitted diseases, and tuberculosis; immunization status; asthma; and pregnancy outcomes.

Usiig a variant of the National Institutes of Health-pioneered consensus-conference format, participants were asked to help BPHC to develop a study agenda to measure the gaps; suggest how the health status measures could be used to evaluate the BPHC's programs; and recommend what measurements and which data sources to use. Panel members were asked to keep in mind BPHC's limited resources and time for any measurements.

II. SPECIFIC CONDITIONS

This section will briefly review the conditions considered. Possible evaluation measures and data sources for each may be found in Exhibits 1 and 2.

A. Diabetes Mellitus (Expert: Charles Clark, M.D., Indiana University)

Minorities and low-income populations are not only more likely to have DM, but they are also more likely to have complications such as blindness, renal disease and microvascular disease. Although diabetes cannot yet be prevented, its complications can be. Recent large-scale studies with Type I diabetes show that SO-70 percent of complications such as blindness, neuropathy, and End Stage Renal Disease can be delayed or prevented through tight control of blood glucose levels; smaller-scale studies suggest similar results with Type II.

B. Hypertension, Cardiovascular Conditions, ahd Cerebrovascular Conditions
(Expert: Paul Sorlie, PhD, National Heart, Lung, and Blood Institute)

Coronary heart disease and stroke show strong relationships to SES status and race/ethnicity. This is also true of most of the underlying risk factors: hypertension, cigarette smoking, obesity, and lack of physical activity. Cholesterol level does not appear to vary with SES status. The incidence and prevalence of both heart disease and stroke for individuals can be largely decreased through prevention or treatment for hypertension and high cholesterol, smoking cessation, reducing obesity and increasing physical activities.

It would be possible to evaluate change in average risk factors among program users, including those cited in Healthy People 2000, such as percent with blood pressure under control, percent taking action to control high blood pressure, percent of smokers taking action to quit, and other risk-reducing behaviors. Since the relationship of these reductions in risk factors to clinical outcomes for groups of patients has been established, they can legitimately serve as sentinels or markers to evaluate BPHC programs.

C. Breast Cancer (Expert: Karen Johnson, MD, PhD, National Cancer Institute)

Although the overall breast cancer incidence rate for Black women is lower than that for White women, Black women have a higher likelihood of being diagnosed with a more advanced stage of breast cancer and of dying from this disease. These outcomes correlate inversely with SES as well. Much of the racial difference in mortality has been attributed to disease stage at time of diagnosis; however, there is also evidence that Black women are less likely to receive aggressive therapies or cancer-directed therapies, and that tumors in Black women may be biologically more aggressive.

The “gold standard” for evaluating breast cancer detection and treatment programs is a

reduction in mortality, but this endpoint requires a relatively large population and an appropriate control group for comparison. Sii mortality is related to mammography and appropriate-treatment rates, these could be used as evaluation tools,

D. Cervical **Cancer (Expert:** Helen Meissner, **PhD,** National Cancer Institute)

Cervical cancer incidence and mortality are related to both minority and SES status. For example, incidence of cervical cancer is higher in Black women than in White women (relative risk of 2.3). Risk of the disease was found to be greatest for Alaskan natives, for whom the relative risk was 2.7. Rates also are high for Hispanics and new immigrants. Incidence has a strong inverse relationship with both education and income. Survival also appears to be better for women in higher education and economic strata.

Deaths from cervical cancer are rare but highly preventable events, making it difficult to use mortality rates for evaluation purposes. An estimation of the proportion of women receiving Pap smears is probably the most feasible method for evaluating if programs are reaching the target population. An additional measure could be the follow-up rates for women with abnormal Pap smears, as well as the entry into appropriate care.

E. Prostate Cancer (Expert: Otis Brawley, MD, National Cancer Institute.)

Prostate cancer disease (or diseases) has variable biologic behavior. Most often prostate cancer is indolent and of no threat to the person who has it. In other words, some prostate cancers need to be treated aggressively, some do not, but current knowledge does not permit distinguishing between them. Technology used in diagnosing prostate cancer is outpacing our knowledge of who needs to be treated and what kinds of prostate cancer need to be treated. Screening for prostate cancer is more likely to pick up those indolent, untreatable prostate cancers: those that did not need to be cured and that would not have threatened the life of the patient. Similarly, debate rages about the most appropriate treatment: watchful waiting, radiation therapy, and surgery, with no currently known clear advantage of any of them over the others. Given the current uncertainty over the efficacy of screening and treatment, conference participants recommended that prostate cancer not be used in the near future to evaluate BPHC programs.

F. Infectious Diseases (Expert: David McBride, **PhD,** Pennsylvania State University)

Infectious diseases, once believed by many to be on the wane, have been increasing dramatically, although they have paused most recently.

For infectious disease such as HIV/AIDS, tuberculosis, sexually transmitted diseases, and pelvic inflammatory diseases, evaluation measures might focus largely on the processes of prevention, screening, entry into care, and compliance with treatment regimens for those found positive. Tuberculosis and STDs are curable; thus far HIV/AIDS can only be managed, although both primary

and secondary prevention are possible. For HIV/AIDS, the proportion of HIV+ pregnant women who comply with AZT therapy could be measured, since such therapy had been shown to greatly reduce the transmission of the virus to the newborns. So, too, could knowledge of risky practices (and acting on that knowledge, for example, through abstinence from high-risk sexual behavior), or the beginning of AZT and other drug therapy, including the use of prophylaxes against opportunistic secondary infections.

G. Immunizations

(Expert: Edmund Maes, PhD, Centers for Disease Control and Prevention)

All types of immunizations demonstrate differentials between lower- and higher-SES status and between minority and majority Americans. However, the rates are not sufficient even among the more privileged groups. These immunizations include: 1) **Childhood Immunizations:** diphtheria, tetanus, pertussis (DTP, DTP-Hib, DtaP4-5); polio (OPV or IPV); hemophilus influenza type b (Hib); measles, mumps, rubella (MMR); hepatitis B (Hep B); 2) **Adolescent Immunizations:** diphtheria, tetanus (Td); Hep B*; MMR2; 3) **Adult Immunizations:** Td, Hep, influenza, pneumococcal disease; and 4) **Women of Childbearing Age and Pregnant women:** Pregnant women should be tested for HbsAg; women of childbearing age should be protected against rubella. To this list will be added the newly approved immunizations, including varicella zoster virus vaccine (VZV) and hepatitis A (HepA). Approvals are expected in 1996 or later for Dtap(13) acellular pertussis, rotavirus, and Lyme disease.

Because of a joint project between BPHC programs in selected states and the Centers for Disease Control and Prevention (CDCP), there is a base of knowledge on which to draw in measuring immunization efforts. CDCP has developed a methodology and software package ("CASA") for such evaluations in children and is collaborating with BPHC in implementing it in community health centers.

H. Asthma

(Expert: Peter Gergen, MD, National Institute of Allergy and Infectious Diseases

Minority and low-SES Americans suffer a disproportionate share of the asthma morbidity and mortality. In a Maryland hospital study, rates for racial groups were equivalent when SES was controlled. Both asthma mortality and excess asthma morbidity are the result of inadequate treatment.

The effectiveness of primary care can be evaluated through the reduction of "unnecessary" medical care (e.g., unscheduled doctor visits, emergency room visits, and hospitalizations). The ultimate measure would be mortality, but this is a very rare event. Present standards of care dictate a decrease in use of oral beta agonists and an increase in the use of inhaled beta agonists, inhaled anti-inflammatory drugs, and peak-flow monitoring. Spacer chambers increase the ability for the medications to reach the lungs.

The use of unnecessary care could be measured through the number of unscheduled visits,

such as in emergency rooms. Inpatient hospitalizations could be measured through discharge summaries, but we should remember that some hospitalizations are necessary and appropriate.

I. Pregnancy Outcomes (Expert: John Kiely, **PhD,** National Center for Health Statistics)

"Pregnancy outcomes" was used in the conference to mean miscarriage, late fetal death (stillborn), congenital malformations, low birth weight (preterm births, and small for gestational age or SGA), infant mortality (neonatal and post-neonatal'), and **"perinatally"** determined neurodevelopmental morbidity (e.g., cerebral palsy).

An important question is whether adverse outcomes are preventable with good primary care. (See Exhibit 1).

EXHIBIT 1
PREVENTIONOFPOORPREGNANCYOUTCOMESBYGOODPRIMARYCARE

Miscarriage	**No**
Late fetal death (stillbom) but badly measured in U.S.	**Yes**
Congenital malformation	**No (except NTDs, preventable through preconceptual care emphasizing proper diet and adequate folk-acid intake)**
Preterm birth	**No**
SGA birth (low birth weight)	**Yes**
Neonatal death	**No/Maybe (depends on system of care)**
Neuro morbidity/cerebral palsy	**No**
Post neonatal death	**Yes**

Thus, the group discussed that the SGA area might prove the most fruitful for evaluating primary care. It appears that the most likely measurements could be the provision of advice and education about smoking and nutrition/weight gain.

J. Other Conditions

In addition to the conditions reviewed by the experts, conference participants suggested several additional conditions: Hepatitis B, pneumonia, oral health, mental health/substance abuse, domestic violence, gastroenteritis, injuries, otitis media, skin rashes, dehydration, sickle cell anemia, other childhood anemia, and non-asthmatic lower respiratory infection.

[1] ***Post-neonatal mortality could*** *be* ***considered a pregnancy outcome (e.g., due to a congenital abnormality) or not related to the pregnancy (e.g., due to unintentional injury of the infant).***

EXHIBIT 2
POSSIBLE MEASURES FOR ASSESSING PRIMARY-CARE

CONDITION	STRUCTURE	PROCESS	INTERMEDIATE OUTCOME	ULTIMATE OUTCOME
Diabetes	Screening Diabetes education Nutrition program Home/community monitoring	Eye exam Foot exam Nutrition counseling Blood-pressure monitoring	Hemoglobin A1 improved Reduced ulcer formation Increased control of hypertension	Reduced amputations Reduced hosp for complications Reduced renal transplantation
Hypertension, cardiovascular & Cerebrovascular Conditions	Smoking cessation program Nutrition program Exercise program	Participation in smoking cessation program Completeness of services	Hypertension and cholesterol: awareness, treatment, control Hypertension treatment Treatment for cholesterol?? Reduced smoking Engaged in physical activity	Reduced hospitalization rate
Breast Cancer	Presence of mammography services (directly or by referral)	Referrals for/receipt of mammograms Follow-up Aggressiveness of treatment	Downward shift in stage of disease over time	Reduced mortality (?)
Cervical Cancer	Availability of Pap smear services Availability of colposcopy	Referrals for/receipt of Pap smears Adequacy of tests Follow-up Aggressiveness of treatment	Downward shift in stage of disease over time(?) Decreased incidence	Regard death as sentinel event
Infectious Disease	Availability of *screening* Continuity of treatment Risk-factor screening	076 compliance (AZT) Treatment and compliance Continuity/completion of treatment	For kids: prevention of hospitalization & dehydration from infections (e.g., gastroenteritis)	Reduced incidence

CONDITION	STRUCTURE	PROCESS	INTERMEDIATE OUTCOME	ULTIMATE OUTCOME
Immunization	Availability of age-appropriate immunizations Tracking system Reminder system	Fewer missed opportunities	Receipt of antigens in timely manner (can choose multiple endpoints)	Reduced incidence of immunizable disease
Asthma	Availability of personnel/program	Administration of appropriate medicines Counseling	Decreased urgent/non-urgent visit ratio; hospitalizations; patient skills measurement; appropriate medical therapy; appropriate environmental interventions	Reduced hospitalization
Pregnancy Outcomes	Nutrition counseling Smoking cessation program Substance abuse program	Participation in: nutrition, smoking cessation, substance abuse programs	Reduction in smoking Weight gain Increased interpartum interval Fewer postneonatal illnesses/injuries	Decreased IMR

III. NEXT STEPS

Participants believed that the next step in BPHC's exploration of using health-status gaps to evaluate primary care programs should be the consideration of what and how much information could be gleaned from each of the available data sources for as many of the selected conditions as possible. This action will then permit BPHC to organize the conditions by measurable points and data sources; and then to define the evaluation questions and develop doable study proposals. In other words, each data set would be mined for as much useful information as possible. In general, the data sources that could be used during evaluations of BPHC programs are:

- The **Uniform Data System,** which is BPHC's new universal system for its grantees, on which they report users and encounters for selected procedures and diagnoses.* Although these are aggregated data, they do lend themselves to analysis of, for example, utilization by condition.

- **The User-Visit Survey,** recently completed, which collects data that can be compared to the National Health Interview Survey and the National Hospital Ambulatory Care Survey.

- **Medicaid claims data can be used to** measure the utilization (by type and diagnoses) and costs to Medicaid for users of community health centers compared to users of other ambulatory care providers. The Medicaid data, are, of course, available only for Medicaid beneficiaries and not the uninsured.

- **Hospital-discharge data** for inpatient care, which can be used for measuring hospitalizations for Ambulatory Care Sensitive Conditions (See Exhibit 5) either in groups or as a whole.[3] They do not, however, identify either the patients' usual source of primary care (hence whether or not they are CHC users).

- **Review of sampled medical records to** provide patient-level data not available through any of the aggregated data bases, such as records of immunizations, blood pressure readings, and eye exams of diabetics. This is probably the richest source of patient-specific data but is also the most expensive to collect on a per-patient basis.

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[2]In addition to the VDS itself, studies might be enriched through using the encounter-level data (i.e., the source data for much of the UDS) from a sample of CHCs.

[3]Ambulatory Care Sensitive Conditions methodology could also be applied to Medicaid claims data, although, to our knowledge, that has not yet been done.

EXHIBIT 2
DATA SOURCES FOR MEASURING CONDITIONS

Data Source	Diabetes	Hypertension, Cardiovascular, Cerebrovascular	Breast Cancer	Cervical Cancer	Infectious Disease	Immunizations	Asthma	Pregnancy Outcomes
Uniform Data System (Users and encounters)	Diabetes encounters and users	Selected heart disease, hypertension	# abnormal breast findings; mammograms	Abnormal cervical findings, pap smears	For HIV/ AIDs, STDs, TB, others	Selected immunizations (not by age)	Asthma users & encounters	Prenatal: age, race/ethnicity, entry into care Outcomes: lack of infant development Health super-vision/infant
User-Visit Survey	demographies, health status, utilization, screening, treatment, education, patient knowledge. Sample data but can be: 1) compared to national surveys of general population; 2) (because individual records) crosstabs and regressions run.							
Medicaid	In- & outpt Comparison group Care source	In- & outpt Comparison group Care source	In- & outpt Comparison group Care source	In- & outpt Comparison group Care source	In- & outpt Comparison group Care source	Whether immun. given, demographics; not which imm.	In- & outpt Comparison group Care source	Use during eligibility Source of care Often not interpartum
Hospital Discharge (inpatient)	Disease progression Complications Procedures	Disease progression Procedures	Disease progression Procedures	Disease progression Procedures	Disease progression Procedures	N/A	Disease control & progression	Mother/infant complications
Medical Records	Eye, foot, BP tests HCI results Disease state Risk factors Demographics	B.P. checks B.P. rates Treatment Risk factors Demographics	Breast exam Mammogram Results Follow-up Referral	Pap smear Results Follow-up Referral	Screening Diagnosis Treatment Demographics	When, what immunization given Missed opportunities Demographics	Diagnosis Treatment Demographics Provision of spacers Emergency/ non-emergency visits	Utilization Risk factors (ID + whether reduced) Pregnancy outcome

ACKNOWLEDGEMENTS

Many people contributed to the success of this consensus conference. Bonnie Lefkowitz and Barbara Wells have led the Bureau of Primary Health Care's team in approaching the issues of health-status gaps and the potential for using them to evaluate BPHC's programs. Anabel Crane and Michael Millman from the Health Services and Resources Administration provided invaluable guidance.

The conference greatly depended on the experts on each condition who presented basic information and then served as resources for the participants' discussions. They were: Charles Clark, Paul Sorlie, Karen Johnson, Helen Meissner, Otis Brawley, David McBride, Edmond Maes, Peter Gergen, and John Kiely. Joanne Lukomnik contributed valuable insights.

Ann Zuvekas and Lea Scarpulla-Nolan of the Center for Health Policy Research of The George Washington University Medical Center organized and facilitated the conference, and also prepared the background papers for participants' use.

Finally, we thank the conference participants themselves, who most generously contributed their time and ideas to helping BPHC set its evaluation agenda.

Consensus Conference of Health Status Gaps of Low-Income and Minority Populations

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Consensus Conference of Health Status Gaps of Low Income and Minority Populations: A Synopsis

December **7-8, 1995**

The Bureau of Primary Health Care (BPHC) convened a meeting of experts to recommend how to proceed in measuring our programs' impact on reducing the health-status gaps between minority or low-socioeconomic status subpopulations and the U.S. population as a whole. Conference participants included epidemiologists, health services researchers, federal program officials, representatives of BPHC's programs (e.g., from community health centers), and people whose expertise is in one health condition or area. (See Appendix A).

BPHC's programs have as one of their goals improving health outcomes and reducing gaps in health status for low income and minority populations. BPHC's programs address this goal by identifying community-wide health problems; providing outreach, education, and preventive/primary care; and reducing the need for more expensive curative services. Measurement of the programs' success in meeting the goal must be increasingly stringent in view of the Government Performance and Results Act (GPRA) requirements and shrinking resources, as well as outcome-driven in view of its scientific validity and marketplace competition.

Outcome measurement is one of six priorities in BPHC's strategic plan. To implement its data and evaluation strategy, BPHC has developed an annual reporting format common to all its programs; conducted a major national survey of programs' users allowing comparisons with the general population; and refocussed its one percent evaluation studies on quantifiable outcomes.

BPHC now has available new data sets that can be tapped for this purpose:

- Uniform Data System, which commenced January 1996 and will be available in spring 1997. This data set provides center-level data on utilization, costs, staffing, and health conditions. Utilization for the most common conditions can be analyzed.

- User/Visit Survey, which is designed to provide data comparable to those collected on the general population through the National Health Interview Survey and the National Hospital Outpatient Ambulatory Care Survey, as well as information about chronic conditions commonly seen in primary care settings.

I. THE PURPOSE OF THE CONFERENCE

BPHC convened this conference to discuss potential measures of primary care outcomes using known health-status gaps in conditions either between majority and minority people in the United States or between those of higher- and lower-socio-economic status (SES). Because the purpose of this meeting was to develop potential measures for assessing BPHC programs at some stage in the condition's progression, primary care must have a significant effect in preventing, treating, controlling, or ameliorating the condition and/or its sequelae. Standards of care must exist before considering a specific condition or disease for inclusion. Using these criteria, the conditions selected for discussion were diabetes; hypertension, cardiovascular, and cerebrovascular conditions; breast, cervical, and prostate cancer; infectious diseases including AIDS, sexually transmitted diseases, and tuberculosis; immunization status; asthma; and pregnancy outcomes.

Using a variant of the National Institutes of Health-pioneered consensus-conference format, the first

time that BPHC has used such an approach, participants were asked to help BPHC to develop a study agenda to measure the gaps; suggest how the health status measures could be used to evaluate the BPHC's programs; and recommend what measurements and which data sources to use. Panel members were asked to keep in mind BPHC's limited resources and time for any measurements.

Specifically, for each condition participants were asked to consider:

- Can the gap(s) in incidence, prevalence, severity, outcome of the condition between low socioeconomic status and minority subpopulations compared with the rest of the U.S. be distinguished?
- Can the condition be prevented, treated, controlled, or ameliorated through effective primary care?
- Can the condition be used to measure the effectiveness of primary care programs? Are there clinical standards of care? What extraneous factors must be considered?
- At what stage(s) in its progression should it be measured? Given BPHC's likely resource constraints, what methods should be used to measure it? Using what data sources? Are there other measurement issues?
- Should the health status of the community or of the program's patients be measured? How large a group would need to be measured?
- What further information should BPHC have before determining that the condition would be a good choice for its purposes?
- What steps would BPHC need to take to make such measurements a reality?

For each condition the conference's format was the presentation of the answers to the above questions by one or more experts in the field, followed by group discussion with the expert serving as resource person.

II. SPECIFIC CONDITIONS

A. Diabetes Mellitus

Charles Clark, MD, Indiana University

Diabetes mellitus (DM) is a common condition, accounting for 10 percent of internist visits and $100 billion in direct and indirect costs annually or 17 percent of all health care costs. The relative risks for incidence of diabetes for Blacks is 2.5, Hispanics 2.5, and some communities of Native Americans as high as 40.0. It is also more common in low socioeconomic status populations, partly because obesity is more common among them. Low birth weight appears to be a risk factor.

Minorities are not only more likely to have DM, but they are also more likely to have complications such as blindness, renal disease and microvascular disease. As with some other conditions discussed at the conference, progression of the disease itself may differ by subpopulation, although it is as yet unclear whether this is a result of genetics or other factors such as access to care or differences in response to medical therapy. Type II diabetics are likely to have co-morbidities, particularly heart disease: 50-60 percent have hypertension, one-third have hyperlipidemia, and 80 percent are obese. People with DM tend to die from cardiovascular disease.

Although diabetes cannot be prevented, except perhaps by control of obesity for Type II, its complications can be. Recent large-scale studies with Type I diabetes show that 50-70 percent of

complications such as blindness, neuropathy, and End Stage Renal Disease can be delayed or prevented through tight control of blood glucose levels; smaller-scale studies suggest similar results with Type II. (The results are not as clear for macrovascular complications, such as heart attacks, strokes, and peripheral vascular disease.)

Primary care is critical to the control of diabetes: 80 percent of Type I and 90 percent with Type II are seen by primary care physicians. Only 3-4 percent are seen by diabetologists.

Standards of care do exist for primary care management of diabetes, but large gaps exist between what is recommended and what is actually done. For example, only half of patients receive the recommended annual eye exams. Education programs are critical, since most patients essentially care for themselves. For example, learning new eating habits can be a challenge.

The following could be used as primary care indicators or process measures: foot examinations, eye examinations, and the taking of blood pressure; secondary prevention could consist of urine protein tests, and hemoglobin Al (blood sugar) measures. These are indicators that secondary prevention is occurring and that complications are likely to be prevented. It is more difficult to measure some complications themselves; for example, the average length of time from diagnosis as a diabetic to onset of retinopathy is 15 years.

The measures could be whether: 1) the procedure, such as hemoglobin Al, is being done (process measure), and 2) the overall clinical results show improvement, such as drop in average hemoglobin Al levels (intermediate outcome). Data to support these measures could come from the encounter forms and/or the medical records. A good database for measuring intermediate outcomes would be longitudinal if a center has unique patient identifying numbers. Establishing such a longitudinal database would be difficult: HMO patients' average length of membership is 18 months. However, BPHC could use patients as the unit of analysis, with only those patients who had at least two hemoglobin Al tests and measure the change in their next hemoglobin Al.

In addition to the process measures (e.g., whether an eye examination was done on schedule) and intermediate outcome measures (e.g., whether blood glucose levels showed better control) for its programs' patients, BPHC might want to use hospital discharge and/or Medicaid data to look for Ambulatory Care Sensitive events in the population. That is, BPHC could measure whether its program was doing a good job (process measures) as well as its effects (outcomes), such as hospitalizations for complications such as ketoacidosis. However, since most complications require relatively long time lapses to appear, care should be taken in considering the length of time that a CHC has been giving care in an area; the results should not be used to measure short-term impact.

B. Hypertension, Cardiovascular Conditions, and Cerebrovascular Conditions

Paul Sorlie, PhD, National Heart, Lung, and Blood Institute

Coronary heart disease and stroke show strong relationships to SES status and race/ethnicity. This is also true of most of the underlying risk factors: hypertension, cigarette smoking, obesity, and lack of physical activity. Cholesterol level does not appear to vary with SES status.

The incidence and prevalence of both heart disease and stroke for individuals can be largely decreased through prevention or treatment for hypertension and high cholesterol, smoking cessation, reducing obesity and increasing physical activities.

Those seeking to develop evaluation measures in this area must select the stage in the progression of the condition: 1) risk factors (e.g., blood pressure, cholesterol, smoking, obesity); 2) subclinical disease (e.g., arterial atherosclerosis, ankle/arm index); 3) clinical events (e.g., myocardial infarction, stroke); and 4) fatality (e.g., sudden death, case fatality). For guidance on the choice of measurement, community clinical studies are helpful:

- The Multiple Risk Factor Intervention Trial tested 12,800 individuals who were randomly assigned to specific interventions or to usual care. After six years, there are significant changes in risk factors but no significant reductions in disease incidence. That little difference was found in the reduction of incidence may be attributable to the fact that both the control and the experimental groups reduced risk factors; however, by the end of 12 years, disease incidence rates had dropped more in the experimental group than in the control group.

- **The Stanford** Five Cities Studies in which interventions were made at the community level (35,000 to 145,000 residents) rather than individuals. Community changes in risk factors were found to be not significant, and changes in incidence of disease could not be measured.

These studies suggest that measuring improvements in community levels of risk factors or community-level incidence of clinical disease would require too much time and resources to be useful to BPHC as for evaluation purposes. Moreover, other problems such as turnover of patients over time and external factors that also affect disease progression, such as the tempo of change in the general population, make it difficult **to use subclinical disease, clinical events, or fatalities as sentinels. BPHC needs to carefully weigh the time needed** for measurement of differences later in the disease progression, as well as the size of the population needed for comparisons.

It would be possible, however, to evaluate change in average risk factors among program users, including those cited in Healthy People 2000:

- Percent with blood pressure under control (target 50 percent) (systolic blood pressure, diastolic blood pressure, compliance with medication).

- Percent taking action to control blood pressure (target 90 percent) (medications, diet for weight loss, reduction in salt intake, exercise).

- Knowledge of blood pressure values (target 90 percent).

- Mean cholesterol level (target <200 mg/dl).

- Percent of population with high cholesterol (target 20 percent).

- Patient awareness of cholesterol level (target 60 percent).

- Prevalence of overweight patients (20 percent).'

- Prevalence of cigarette smoking (15 percent).

- Percentage engaging in moderate physical activity (30 percent).

Since the relationship of these reductions in risk factors to clinical outcomes for groups of patients has been established, they can legitimately serve as sentinels or markers to evaluate BPHC programs. It may be important to study multiple risk factors together, rather than just one or two. They could be studied for BPHC populations in general or specific target groups, such as middle-age males, in particular. BPHC may wish to collect data for both genders and all age groups and then

'Some participants believed it to be difficult to evaluate BPHC programs on obesity levels, since so many confounding variables exist. However, most participants agreed that such a measure should definitely be included if and when efficacious treatment standards exist.

analyze them for specific groups.

Data sources could include the User/Visit Survey (and comparison to the general population from the National Health interview Survey and the National Ambulatory Hospital Outpatient Survey), perhaps combined with chart review and/or measurement of blood pressure, cholesterol, etc. One major measurement issue is the need for standardizing risk-factor measurements, such as plasma or serum cholesterol, use of a single laboratory, and training of blood-pressure observers.

C. Breast Cancer

Karen Johnson, MD, PhD, National Cancer Institute

Unlike the medical conditions discussed above, the overall breast cancer incidence rate for Black women is lower than that for White women. However, Black women have a higher likelihood of being diagnosed with a more advanced stage of breast cancer and of dying from this disease. These outcomes correlate inversely with SES as well. Much of the racial difference in mortality has been attributed to disease stage at time of diagnosis; however, there is also evidence that Black women are less likely to receive aggressive therapies or cancer-directed therapies, and that tumors in Black women may be biologically more aggressive.

Although 1990 data from the National Health Interview Survey for screening mammography in the past year show a similar level of use by Black and White women, the same data source indicates that women with lower education or income are less likely to be screened. In the portion of the population not using screening mammography, differences in using the medical system to evaluate breast problems could also result in relatively later diagnosis of the disease.

The "gold standard" for evaluating breast cancer detection and treatment programs is a reduction in mortality, but this endpoint requires a relatively large population and an appropriate control group for comparison. Interpretation of survival rates based, for example, on the number of breast-cancer patients living after five years from the time of diagnosis, can be flawed by several biases including lead time and length time. Similarly, incidence rates may be difficult to interpret due to temporary fluctuations related to increased screening activity* or the possibility of overdiagnosis, i.e., identification of less aggressive lesions that make a smaller contribution to mortality. These outcomes are related to several process variables which include mammography rates, primary therapy rates, adjuvant therapy rates, and other measures of quality of care.

Since mortality is related to mammography and appropriate-treatment rates, these could be used as evaluation tools. Early detection from increased mammographic screening can reduce mortality by 30-35 percent and is relatively easy to measure through either chart reviews or patient recall; the latter may be preferable since women tend to remember a mammogram. The User-Visit Survey includes pertinent information. The resultant disease stage at time of diagnosis could also be used as a measure.

In addition to the above, BPHC might also choose to monitor primary therapy rates[3] and adjuvant therapy rates, although this would be difficult since, once a patient is referred to specialists

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[2] *In a steady-state situation, increased screening identifies cases earlier in the preclinical phase, with a temporary increase in incidence, which returns to baseline as the pool of cases detectable with the increase in screening is exhausted.*

[3] *Unfortunately, evidence of the relationship of treatment differentials to mortality rates has not yet been established, primarily due to the relatively small number of cases.*

outside the center, it is very difficult for the center to monitor that treatment. On the other hand, it would be possible to use process characteristics (e.g., referral and receipt-of-treatment rates for those with positive mammographies).

D. Cervical Cancer

Helen Meissner, PhD, National Cancer Institute

Cervical cancer incidence and mortality are related to both minority and SES status. For example, incidence of cervical cancer is higher in Black women than in White women (relative risk of 2.3). Risk of the disease is found to be greatest for Alaskan natives, for whom the relative risk is 2.7. Rates also are high for Hispanics and new immigrants. Incidence has a strong inverse relationship with both education and income. Survival also appears to be better for women in higher education and economic strata.

Deaths from cervical cancer are rare but highly preventable events, making it difficult to use mortality rates for evaluation purposes. However, BPHC could treat each death as a sentinel event and follow up to see where the system failed. One must keep in mind, though, that women who die of cervical cancer do not represent the current situation, but rather screening and treatment received in prior years. While incidence rates may indicate the extent of a cervical cancer problem in the populations, these data are less widely available and are of less reliable quality than mortality data.

An estimation of the proportion of women receiving Pap smears is probably the most feasible method for evaluating if programs are reaching the target population, however it may be defined. As was the case for the other measures discussed, the denominator (population covered by the screening program) must be defined (e.g., CHC users vs. community population) before rates can be calculated and comparisons made. Chart audits may tease out how many Pap smears provided by the health center are multiple tests for the same woman. Participants noted that self-reporting of Pap smears may not be accurate, since women tend to telescope receipt of the test (i.e., report that they had the test more recently than they actually did). Also, studies indicate that some women overreport use of the test because they confuse pelvic exams with Pap smears. Still, self-reports are commonly used to count the number and rate of Pap smears, so that comparisons with other data sets would be possible. The chart reviews could also estimate the extent of overreporting.

An additional measure could be the follow-up rates for women with abnormal Pap smears, as well as the entry into appropriate care. Evaluators could compare BPHC program rates with those of other providers for the same populations, perhaps through the use of the Medicaid files. It may also be possible to measure progress over time in identifying the disease at earlier stages and compare the results to SEER data; however, a multitude of measurement problems (e.g., correct diagnosis of the stage, difficulty in assuring that referral results are fed back to the BPHC grantee) may severely hamper the use of staging as a tool.

E. Prostate Cancer

Otis Brawley, MD, National Cancer institute

Prostate cancer also shows a much higher incidence rate among minorities: twice the incidence as for White males. However, the gap is closing: in 1980 the Black-to-White ratio was 1.6/1.0, while by 1990 the ratio had narrowed to 1.3/1 .O. By 1995 the gap may have closed completely, in large part because Whites are tested more than Blacks.[4] Survival rates among Blacks are lower than among Whites: Blacks have a 66.4 percent five-year survival rate versus 81.3 percent for Whites. Family history, benign prostate hyperplasia, poverty, and occupation are all among the risk factors, but the greatest risk factor is age: 30 percent of men over age 50 have prostate cancer.

The disease appears to be increasing, but this is likely to be illusory. The 1990 new diagnosis estimate was 106,000 men, the 1995 estimate 317,000 men. However, this is likely to be due to the ease of diagnosis, not because of increased prevalence. Similarly, in 1990 there were 30,000 deaths, in 1995 40,400 deaths. However, some men are counted as dying of prostate cancer when they actually died with prostate cancer since a metastasized cancer is often listed as the primary cause of death even if the proximate cause was another disease entirely.[5]

"Many observers believe that apparent rises in prostate cancer rates *over the past fen years are due to better and more frequent testing, rather than actual increases in incidence. If that is true, then the higher proportions of White men who are being tested could account for their apparently closing the gap with Black men.*

[5]*This is true for all cancers. However, because of the* **variable nafural** *history of* prostatic cancer, many men *have prostatic cancer at time of death but it may not have been clinically significant or the disease may not have contributed to the cause of death.*

The disease (or diseases) has variable biologic behavior. Most often prostate cancer is indolent and of no threat to the person who has it. In other words, some prostate cancers need to be treated aggressively, some do not, but current knowledge does not permit distinguishing between them. Technology used in diagnosing prostate cancer is outpacing our knowledge of who needs to be treated and what kinds of prostate cancer need to be treated. Screening for prostate cancer is more likely to pick up those indolent, untreatable prostate cancers: those that did not need to be cured and that would not have threatened the life of the patient.

This uncertainty has led to much debate in the field as to the place of screening, since screening does not appear to save lives. Similarly, debate rages about the most appropriate treatment: watchful waiting, radiation therapy, and surgery, with no currently known clear advantage of any of them over the others. Fifteen of 18 national organizations with an interest in the area agree that insufficient evidence exists that current screening practices lower mortality. Trials currently underway may shed some light,

Given the current uncertainty over the efficacy of screening and treatment, conference participants recommended that prostate cancer not be used in the near future to evaluate BPHC programs.

F. Infectious Diseases

David McBride, PhD, Pennsylvania State University

Infectious diseases, once believed by many to be on the wane, are increasing dramatically. From 1980 to 1992, the mortality rate from infectious diseases as the underlying causes of death increased 58 percent, from 41 deaths per 100,000 to 65; when age-adjusted, the rates increased 39 percent over the period. The most significant increase was due to AIDS, but, even without its contribution, rates for other infections also rose. By 1992 Blacks had a mortality rate with infectious disease as the underlying cause of 88 per 100,000, or 36 percent higher than the national rate.

For infectious diseases the conference applied the same criteria for consideration as it did for all other conditions." These criteria led to a focus on HIV/AIDS infection, tuberculosis, and sexually transmitted diseases (STDs). HIV/AIDS is especially important because of the significant recent increases in poor and minority populations. Pelvic inflammatory disease was included because its major etiology is from the contracting of STDs

Although both minority and low-SES Americans have a higher incidence of infectious disease than do majority and higher-SES Americans, much of the difference is related to SES status. Tuberculosis, sexually transmitted diseases (STDs), and HIV/AIDS all are more prevalent among minority and poor Americans than among Whites and higher-SES Americans. For example, primary and secondary syphilis occurs 45 times as often among non-Hispanic Blacks and 13 times as often among Hispanics as among non-Hispanic Whites. The three types of disease are related: infection by STDs can increase opportunities for infection by the HIV virus; in turn, the weakening of the immune system by the AIDS virus can permit tuberculosis to infect the patient.

From the mid-1950s to the mid-1980s tuberculosis rates were declining, but since then rates have again been rising, particularly among Blacks, migrants, and new immigrants. Moreover, by 1995 some 6 percent of cases were found to be multidrug resistant.

For all these diseases, evaluation measures might focus largely on the processes of prevention, screening, entry into care, and compliance with treatment regimens for those found positive. Tuberculosis and STDs are curable; thus far HIV/AIDS can only be managed, although both primary and secondary prevention are possible. For HIV/AIDS, the proportion of HIV+ pregnant women who comply with AZT therapy could be measured, since such therapy had been shown to greatly reduce the transmission of the virus to the newborns. So, too, could knowledge of risky practices (and acting on that knowledge, for example, through abstinence from high-risk sexual behavior), or the beginning of AZT and other drug therapy, including the use of prophylaxes against opportunistic secondary infections.

Data to support these process measures could be gathered from medical records. Some Health Maintenance Organizations are requiring that such data be kept; these organizations could be queried about the availability of the data, particularly if they permitted comparisons among provider types.

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[6] *Health-status gaps musf exisf befween minority and low SES persons and the majority populations; at some stage in the condition's progression, primary care must have a significant effect in preventing, treating, controlling, or ameliorating a condition and/or its sequelae; and standards of care must exist before considering a condition for inclusion.*

G. Immunizations

Edmond Maes, PhD,
Centers for Disease Control and Prevention

All types of immunizations demonstrate differentials between lower- and higher-SES status and between minority and majority Americans. However, the rates are not sufficient even among the more privileged groups. These immunizations include:

- **Childhood Immunizations:** diphtheria, tetanus, pertussis (DTP, DTP-Hib, DtaP4-5); polio (OPV or IPV); hemophilus influenza type b (Hib); measles, mumps, rubella (MMR); hepatitis B (Hep B).

- **Adolescent Immunizations:** diphtheria, tetanus (Td); Hep B*; MMR2.

- **Adult Immunizations:** Td, Hep, influenza, pneumococcal disease.

- **Women of Childbearing Age and Pregnant women:** Pregnant women should be tested for HbsAg; women of childbearing age should be protected against rubella.

To this list will be added the newly approved immunizations, including varicella zoster virus vaccine (VZV) and hepatitis A (HepA). Approvals are expected in 1996 or later for Dtap(I-3) acellular pertussis, rotavirus, and Lyme disease.

Low immunization coverage can be ameliorated through effective primary care, through such actions as assessing immunization status at each visit, eliminating false contraindications as a reason for not immunizing (e.g., minor illness), using compressed immunization schedules when children are behind schedule, and implementing a reminder and recall system to improve appointment attendance and clinician behavior. These actions can be encouraged by assessing vaccination coverage in provider practices. There is also an opportunity to improve clinical practice based on feedback of results, identifying and **implementing programs to change practices, and** subsequently measuring impact of intervention. It is important for centers to maintain adequate and accessible medical charts (e.g., immunization cover sheet at the front of chart) and to update the written, parent-held immunization record at each visit.

Immunizations can be used to measure primary care practice, particularly since well-developed standards of care exist in immunizations schedules such as those from the American Academy of Pediatrics, the American College of Physicians, and the U.S. Preventive Services Task Force.

Some extraneous factors must be considered, including the mobility of the population to be served, the division of labor between health departments and primary care providers, and contraindications and refusal of immunizations.

Evaluators can measure either the immunization rates at one point in time or longitudinally through sampling clinic or provider records and measuring: age-specific antigen coverage levels; start of immunizations (e.g., DTP1 coverage at 3 months of age); drop-out rate (DTP1-DTP3 coverage at 12 months of age; DTP1-MMR1 coverage at 18 months of age; DTPI-DTP4 at 24 months of age). (See Exhibit 1).

Because of a joint project between BPHC programs in selected states and the Centers for Disease Control and Prevention (CDCP), there is a base of knowledge on which to draw in measuring immunization efforts. CDCP has developed a methodology and software package ("CASA") for such evaluations in children and is collaborating with BPHC in implementing it in community health centers. Any measure requires 100 to 200 records per age group of interest per clinic. Population-based methods include telephone surveying, but this requires a very large **number and excludes people who do not** have

telephones. Community door-to-door surveys are difficult and may be best conducted in conjunction with a community-wide immunization campaign.

Data from any of these sources will be improved through checking written immunization cards, retrieving information from other providers, and validating verbal reports and parent-held records by obtaining provider records.

The following steps are being taken to make these measurements a reality: 1) training state primary care association and clinical network personnel or contractors in the use of CASA; 2) using the CASA "diagnostic report" to determine areas for improvement; 3) beginning routine systems for periodic measurement of coverage levels linked with quick feedback and interpretation of results; and 4) integrating measures of immunization in the BPHC clinical measures program.

EXHIBIT 1. Immunization Evaluation Points

PRESCHOOLERS	Age at Measurement
DTP1, HepB1	3 months, 12 months
DTP3, OPV3, Hib2, HepB3 *	12 months
DTP3, OPV, Hib3, HepB3, MMR1 *	16 months
DTP4, OPV3, Hib3, HepB3, MMR1 *	24 months
SCHOOL-AGE	
DTP5, OPV4, HepB3, MMR2 *	4-6 yrs
ADOLESCENT	
HepB3, MMR2**, Td	11-12 yrs
ADULTS	
HepB3 (high risk groups)	? arbitrary age
Td	once in last 10 yrs
MMR	women of childbearing age
ELDERLY **(> 65 yrs of age)**	
Influenza	1 dose in last year
Pneumococcal	1 dose (since 65 yrs age)
FOR PREVENTION OF **PERINATAL HepB** Screen all pregnant women for HepB surface Ag (HBsAg) Newborns of HBsAg positive mothers should receive HepB Immune Globulin at birth and should begin HepB immunization with high dose HepB vaccine.	

* Should be compiled by Ag and by combined antigens

** Pregnant women should be tested for HbsAg; women of childbearing age should be protected against rubella.

H. Asthma

Peter Gergen, MD, National Institute of Allergy and Infectious Diseases

Minority and low-SES Americans suffer a disproportionate share of the asthma morbidity and mortality. In a Maryland hospital study, rates for racial groups are equivalent when SES was controlled. Both asthma mortality and excess asthma morbidity are the result of inadequate treatment. The issue is largely one of access to appropriate care: low-SES and minority subpopulations are less able to access primary care or, if they do, it is more likely to be in hospitals or clinics that do not use the latest treatments. Asthma specialists (allergists and pulmonologists) tend to use the most current, up-to-date methods of treatment.

Asthma can be effectively treated in primary care settings using relatively inexpensive technology. This requires patients (and/or parents) and providers who are knowledgeable about the disease and a system that will pay for the necessary drugs, peak-flow meters, and spacers.

The effectiveness of primary care can be evaluated through the reduction of "unnecessary" medical care (e.g., unscheduled doctor visits, emergency room visits, and hospitalizations). The ultimate measure would be mortality, but this is a very rare event (0.08 per person/year in a Washington State study and a total of only 5,000 annual deaths in the U.S.) Present standards of care dictate a decrease in use of oral beta agonists and an increase in the use of inhaled beta agonists, inhaled anti-inflammatory drugs, and peak-flow monitoring. Spacer chambers increase the ability for the medications to reach the lungs.

The use of unnecessary care could be measured through the number of unscheduled visits, such as in emergency rooms. For example, if a prescription is filled in an emergency department or urgent care center, then it is likely to have been an unscheduled visit. Potential data sources include the National Health Interview Survey compared to the BPHC User-Visit Survey; Medicaid claims files (or other charge data); and medical records. The first two data sources would permit comparison with similar populations, although it is impossible to determine the denominator of the total asthma population.[7] The best patient/parent questions are those asking about wheezing, morning tightness in the chest, and persistent coughs.

Inpatient hospitalizations could be measured through discharge summaries, but we should remember that some hospitalizations are necessary and appropriate. In addition, at least in New York City asthma hospitalization rates for both low- and high-income populations have been rising, which confounds the measurement of rate changes over time for subpopulations and may suggest other environmental factors, such as indoor and outdoor air quality.

Medical records could also be reviewed for increased numbers or proportions of scheduled to unscheduled visits, the provision of spacers, and for use of anti-inflammatories. For children, functional status measures could include the number of school days missed, the number of parents' work days missed, and whether the child can play in gym class, although it would be difficult to determine if these were asthma-related.

Evaluators also might wish to examine structural elements, such as the presence of appropriately trained nurses in the center.

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[7] *This is largely the reason that asthma was rejected as an indicator for the performance of managed care plans under the HEDIS system.*

I. Pregnancy Outcomes

John Kiely, PhD, National Center for Health Statistics

"Pregnancy outcomes" was used in the conference to mean miscarriage, late fetal death (stillborn), congenital malformations, low birth weight (preterm births, and small for gestational age or SGA), infant mortality (neonatal and post-neonatal), and "perinatally" determined neurodevelopmental morbidity (e.g., cerebral palsy). Exhibit 2 summarizes the relationship between race/ethnicity of the mother, as well as her SES status, and these events.

EXHIBIT 2. Race/Ethnic@, SES, and Pregnancy Outcomes

OUTCOME	RACE/ETHNICITY	SES
Miscarriage	No?	No?
Late Fetal Death	Yes	Yes
Congenital Malformation	Mostly no	A little
Preterm Birth	Yes	Yes
SGA Birth	Yes	Yes
Neonatal death	Yes	Yes
Post neonatal	Yes	Yes
Neuro Morbidity/Cerebral Palsy	No	No

Post-neonatal mortality could be considered a pregnancy outcome (e.g., due to a congenital abnormality) or not related to the pregnancy (e.g., due to unintentional injury of the infant).

As Exhibit 2 shows, a pattern emerges for late fetal deaths, preterm births, SGA, and neonatal and post-neonatal deaths. There is a 50 percent excess in low-SES Whites versus middle- to high-SES Whites; overall, however, Whites in both mid/high- and low-SES cohorts have fewer late fetal deaths, preterm births, SGA and neonatal deaths than both the mid/high- and low-SES groups of Blacks. For these same outcomes, most Asian groups have lower rates than whites (except for SGA); Mexican-Americans are about the same as non-Hispanic Whites; and Puerto Ricans, American Indians, Hawaiians have rates midway between non-Hispanic Whites and Blacks. In most racial/ethnic groups, first-generation Americans have lower rates. For post-neonatal mortality SES differences are striking in all racial/ethnic groups, including Blacks; rates are about the same in college-educated Whites and Blacks.

An important question is whether adverse outcomes are preventable with good primary care. (See Exhibit 3)

EXHIBIT 3. Prevention of Poor Pregnancy Outcomes by Good Primary Care

Miscarriage	No
Late fetal death (stillborn) but badly measured in U.S.	Yes
Congenital malformation	No (except NTDs, which are preventable through preconceptua! care which emphasizes proper diet and adequate folic-acid intake)
Preterm birth	No
SGA birth (low birth weight)	Yes
Neonatal death	No/Maybe (depends on system of care)
Neuro morbidity/cerebral palsy	No
Post neonatal death	Yes

For purposes of evaluating primary care:

- **Late fetal death** has insurmountable measurement and comparability problems.

- **SGA** is preventable through adequate prenatal care, especially through advice to stop smoking and encouragement to gain weight. SGA should reflect the same standard for all racial/ethnic groups, such as below the tenth percentile for gestational age; a proxy might be full-term low birthweight. Gestational age measurement using last menstrual period is not really a problem, if we remember that this is a screen not a diaanosis.

- **Post-neonatal mortality** is largely preventable through well-baby care and is a good measure of primary care effectiveness. The measure should be limited to those infants born at >2500 grams to screen out the low birthweight survivors; it should also exclude deaths from congenital malformation. However, the numbers of deaths are very small, so that we should consider treating the deaths themselves as sentinel events rather than calculating mortality rates.

- **Adolescent pregnancy rates** are often suggested as measures of prevention. However, the denominator could be a problem in evaluating BPHC programs, since the programs are likely to attract -- indeed, seek out -- pregnant teens. One way around this problem would be to include in the denominator only those teens who were BPHC patients before they became pregnant.

- **Maternal mortality** might be considered a sentinel event since it is so rare.

Thus, the group discussed that the SGA area might prove the most fruitful for evaluating primary care. It appears that the most likely measurements could be the provision of advice and education about smoking and nutrition/weight gain. Data sources could include the User/Visit Survey and the medical records.

Some conference participants cautioned, however, that people regularly underreport behaviors such as smoking, particularly for times such as pregnancy when abstention is recommended.

One further note: at birthweights under 2000 grams, Black infants have lower neonatal mortality rates than do White infants, if there is equal access to care. Since much of this is a reflection of access to neonatal intensive care -- rather than to primary care -- it is not a useful measure for evaluating primary care. It may be, however, an indicator of the availability of services in safety-net institutions such as public hospitals as funds become less available for their support.

J. Other Conditions

In addition to the conditions reviewed by the experts, conference participants suggested several additional conditions: Hepatitis B, pneumonia, oral health, mental health/substance abuse, domestic violence, gastroenteritis, injuries, otitis media, skin rashes, dehydration, sickle cell anemia, other childhood anemia, and non-asthmatic lower respiratory infection. Participants also suggested that age groups be considered separately, particularly to capture the differences between adolescents and adults.

Some of these conditions (e.g., otitis media) seemed to be useful for measuring clinical quality but not necessarily outcomes. The differences become clearer when the conditions were categorized by structure, process, intermediate outcome and health status outcome. The presence of a reasonable outcome that could be measured in relation to health center interventions was considered essential for this exercise. (See Exhibit 4.) Others of the suggested conditions have outcomes but are not currently addressed by all centers (e.g., mental health, domesticviolence).

EXHIBIT 4. Possible Measures for Assessing Primary-Care

EXHIBIT 4. Possible Measures for Assessing Primary-Care

CONDITION	STRUCTURE	PROCESS	INTERMEDIATE OUTCOME	ULTIMATE OUTCOME
Diabetes	Screening Diabetes education program Nutrition program Home/community monitoring	Eye exam Foot exam Nutrition counseling Blood-pressure monitoring	Hemoglobin Al improved Reduced ulcer formation Increased control of hypertension	Reduced amputations Reduced hosp for complications Reduced renal transplantation
Hypertension, Cardiovascular & Cerebrovascular Conditions	Risk-factor screening Smoking cessation program Nutrition program Exercise program	Participation in smoking cessation program Completeness of services	Hypertension and cholesterol: awareness, treatment, control Treatment for high cholesterol Reduced smoking Engaged in physical activity	Reduced hospitalization rate
Breast Cancer	Presence of mammography services (directly or by referral)	Referrals for/receipt of mammograms Follow-up of abnormal mammogram Aggressiveness of treatment	Downward shift in stage of disease over time	Reduced mortality
Cervical Cancer	Availability of Pap smear services Availability of colposcopy	Referrals for/receipt of Pap smears Adequacy of tests Follow-up Aggressiveness of treatment	Downward shift in stage of disease over time	Regard death as sentinel event

EXHIBIT 4. Possible Measures for Assessing Primary-Care

CONDITION	STRUCTURE	PROCESS	INTERMEDIATE OUTCOME	ULTIMATE OUTCOME
Infectious Disease	Availability of screening Continuity of treatment Risk-factor screening	076 compliance (AZT) Treatment and compliance Continuity/completion of treatment	For kids: prevention of hospitalization & dehydration from infections (e.g., gastroenteritis)	Reduced incidence
Immunization	Availability of age-appropriate immunizations Tracking system Reminder system	Fewer missed opportunities	Receipt of antigens in timely manner (can choose multiple endpoints)	Reduced incidence of immunizable disease
Asthma	Availability of personnel/ program	Administration of appropriate medicines Counseling	Decreased urgent/non-urgent visit ratio; hospitalizations; patient skills measurement; appropriate medical therapy; appropriate environmental interventions	Reduced hospitalization
Pregnancy Outcomes	Nutrition counseling Smoking cessation program Substance abuse program	Participation in: nutrition, smoking cessation, substance abuse programs	Reduction in smoking Weight gain Increased interpartum interval Fewer postneonatal illnesses/injuries	Decreased IM R

III. CROSS-CUTTING ISSUES

Throughout the conference, participants discussed issues that cut across multiple conditions. Although consensus among participants did not always exist, they believed it important to record the issues for later review by BPHC. These crosscutting issues included:

- **Standards of practice vs. effectiveness measures:** Although it is necessary to have agreement on how primary care should be practiced for a particular condition in order for that condition to be included in BPHC's evaluation plan, the standard should not necessarily equal the evaluation measure. For example, a standard for asthma care might include the use of inhalant spacers, but the measure might be the proportion of visits to acute care settings rather than the use of the spacers per se; use of the broader measure also addresses such issues as the effectiveness as the appointment-reminder system and the accessibility of corticosteroids.

- **Denominator/comparison group:** For all conditions, determining the denominator (e.g., all persons with a particular condition in a center's population) and appropriate comparison groups is a serious challenge.

- **Local-area variation:** The underlying incidence of disease, the aggressiveness of screening for the condition, mortality rates, and health professional practice patterns (e.g., whether to hospitalize) vary enormously across the country, so that cross-geographic comparisons will probably not work in many instances. On a more micro level, variations also exist among laboratories for some tests, which makes cross-lab comparisons difficult.

- **Penetration:** The measurement of community impact is complicated by many issues, but especially by penetration. The greater the penetration of the BPHC into the target population, the greater the impact that can be expected. Since in urban areas the programs often supply about 15-20 percent of the neighborhood's primary care due to constrained resources, how much impact on the overall population can we expect? This also raises that probability of self-selection bias on the part of patients. The problem is less acute in rural areas, where the programs likely supply a greater proportion of the area's primary care.

- **"Gaps" in rural areas:** In some rural areas the narrowing of gaps between majority and minority subpopulations or between those of higher- and lower-SES status may not be appropriate goals. BPHC programs in some rural areas are more likely than their urban counterparts to be located in communities with few minorities and limited numbers of low-income people.

- **Adequacy/comparability of information:** even for relatively simple things like height and weight comparability is a problem (e.g., with or without shoes or clothes). This is true within one clinical setting and, more importantly, across settings.

- **Emphasis on the clinical:** Although BPHC programs are designed to provide health care rather than simply medical care and include "enabling services" such as outreach, translation, transportation, and case management, most of the conference focused on clinical interventions because the task at hand was to devise health outcome measures. This may be appropriate when considering the audiences for much of the evaluation, but it does omit a large part of what is essential to BPHC programs. Similarly, the issue of cultural competence was not addressed. On the other hand, the clinician-participants pointed out that effective non-clinical services should have positive effects on health outcomes, so that they can be measured indirectly.

IV. NEXT STEPS

After discussion, participants believed that the next step in BPHC's exploration of using health-status gaps to evaluate primary care programs should be the consideration of what and how much information could be gleaned from each of the available data sources for as many of the selected conditions as possible. This action will then permit BPHC to organize the conditions by measurable points and data sources, and then to define the evaluation questions and develop doable study proposals. In other words, each data set would be mined for as much useful information as possible.

In general, the data sources that could be used during evaluations of BPHC programs are:

- **The Uniform Data System,** which is BPHC's new universal system for its grantees, on which they report users and encounters for selected procedures and diagnoses.* Although these are aggregated data, they do lend themselves to analysis of, for example, utilization by condition. Furthermore, they could be helpful in constructing sample frames for other studies, such as medical chart reviews.

- **The User-Visit Survey,** recently completed, which collects data that can be compared to the National Health Interview Survey and the National Hospital Ambulatory Care Survey. The first is accomplished through patient interviews, the second through brief reports of patient encounters. Although this is not yet a longitudinal study, it does permit cross-sectional comparisons to other populations and providers.

- **Medicaid claims data** can be used to measure the utilization (by type and diagnoses) and costs to Medicaid for users of community health centers compared to users of other ambulatory care providers. The Medicaid data, are, of course, available only for Medicaid beneficiaries and not the uninsured, but they are a usable and relatively inexpensive source of comparative information. They are most useful for data on women of childbearing age and children and less useful for chronic conditions of the middle-aged male.

- **Hospital-discharge data** for inpatient care, which can be used for measuring hospitalizations for Ambulatory Care Sensitive Conditions (See Exhibit 6) either in groups or as a whole.[9] They do not, however, identify either the patients' usual source of primary care (hence whether or not they are CHC users) or the patients' addresses in areas smaller than zipcodes. In some urban areas zip codes may greatly exceed the centers' service areas, so that the CHCs' health-status impacts (i.e., in preventing disease progression so that hospitalization becomes necessary) are too diluted to measure.

- **Review of sampled medical records** to provide patient-level data not available through any of the aggregated data bases, such as records of immunizations, blood pressure readings, and eye exams of diabetics. This is probably the richest source of patient-specific data but is also the most expensive to collect on a per-patient basis.

Exhibit 5 summarizes the utility of these sources for each condition. Exhibit 6 displays the Ambulatory Care Sensitive Conditions.

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[8] In addition to the UDS itself, studies might be enriched through using the encounter-level data (i.e., the source data for much of the UDS) from a sample of CHCs.

'Ambulatory Care Sensitive Conditions methodology could also be applied to Medicaid claims data, although, to our knowledge, that has not yet been done.

EXHIBIT 5. Data Sources for Measuring Conditions

Data Source	Diabetes	Hypertension, Cardiovascular, Cerebrovascular	Breast Cancer	Cervical Cancer	Infectious Disease	Immunizations	Asthma	Pregnancy Outcomes
Uniform Data System (Users and encounters)	Diabetes mellitus users and encounters	Selected heart disease, hypertension	Number abnormal breast findings; mammo-grams	Abnormal cervical findings, pap smears	For HIV/ Al Ds, STDs, TB, others	Selected immunizations (not by age)	Asthma users and encounters	Prenatal: age, race/ethnicity entry into care. Birth Outcomes lack of infant development Health super-vision of infant
User-Visit Survey	demographics, health status, utilization, screening, treatment, education, patient knowledge. Sample data but can be: 1) compared to national surveys of general population; 2) (because individual records) have crosstabs and regressions run.							
Medicaid	Utilization (in- & outpatient) Comparison group Source of care	Utilization (in- & outpatient) Comparison group Source of care	Utilization (in- & outpatient) Comparison group Source of care	Utilization (in- & outpatient) Comparison group Source of care	Utilization (in- & outpatient) Comparison group Source of care	Whether, where immunization given with demographics; not which immunization	Utilization (in- & outpatient) Comparison group Source of care	Utilization after eligibility determined Source of care Often not interpartum
Hospital Discharge (inpatient)	Disease control & progression Compli-cations Procedures	Disease control & progression Procedures	Disease control & progression Procedures	Disease control & progression Procedures	Disease control & progression Procedures	N/A	Disease control & progression	Mother/infant complications

EXHIBIT 5. Data Sources for Measuring Conditions

Data Source	Diabetes	Hypertension, Cardiovascular, Cerebrovascular	Breast Cancer	Cervical Cancer	Infectious Disease	Immunizations	Asthma	Pregnancy Outcomes
Medical Records	Eye, foot, B.P. tests HCl results Disease state Risk factors Demo-graphics	B.P. checks B.P. rates Treatment Risk factors Demographics	Breast exam Mammo-gram Results Follow-up Referral Demo-graphics	Pap smear Results Follow-up Referral Demo-graphics	Screening Diagnosis Treatment Demo-graphics	When, what immunization given Missed opportunities Demographics	Diagnosis Treatment Demo-graphics Provision of spacers Emergency/ non-emergency visits Demo-graphics	Utilization Risk factors (ID + whether reduced) Pregnancy outcome Demo-graphics

EXHIBIT 6. Ambulatory Care Sensitive Conditions

ACS Condition and ICD-9-CM Code(s)	Comments
Congenital syphilis [090]	Secondary diagnosis for newborns only
Immunization-related and preventable conditions [033, 037, 045, 320.0, 390, 391]	Hemophilus meningitis [320.2] age 1-5 only
Grand mal status and other epileptic convulsions [345]	
Convulsions "A" [780.3]	Age O-5
Convulsions "B" [780.3]	Age >5
Severe ENT infections [382, 462, 463, 465, 472.11	Exclude otitis media cases [382] with myringotomy with insertion of tube [20.01]
Pulmonary tuberculosis [011]	
Other tuberculosis [012-018]	
Chronic obstructive pulmonary disease [491, 492, 494, 496, 466.01	Acute bronchitis [466.0] only with secondary diagnosis of 491,492, 494, 496
Bacterial pneumonia [481, 482.2, 482.3, 482.9, 483, 485, 486]	Exclude case with secondary diagnosis of sickle cell [282.6] and patients <2 months
Asthma [493]	
Congestive heart failure [428, 402.01, 402.11, 402.91, 518.41	Exclude cases with the following surgical procedures: 36.01, 36.02, 36.05, 36.01, 37.5, or 37.7
Hypertension [401.0, 401.9, 402.00, 402.10, 402.901	Exclude cases with the following procedures: 36.01, 36.02, 36.05, 36.01, 37.5, or 37.7
Angina [411.1, 411.8, 413]	Exclude cases with a surgical procedure [01-86.991

EXHIBIT 6. Ambulatory Care Sensitive Conditions

ACS Condition and ICD-9-CM Code(s)	Comments
Cellulitis [681, 682, 683, 686]	Exclude cases with a surgical procedure [OI-86.991, except incision of skin and subcutaneous tissue [86.0] where it is the only listed surgical procedure
Skin grafts with cellulitis [DRG 263, DRG 264]	Exclude admissions from SNF/ICF
Diabetes "A" [250.1, 250.2, 250.31	
Diabetes "B" [250.8, 250.91	
Diabetes "C" [250.0]	
Hypoglycemia [251.2]	
Gastroenteritis [558.9]	
Kidney/urinary infection [590, 599.0, 599.91	
Dehydration - volume depletion [276.5]	Examine principal and secondary diagnoses separately
Iron deficiency anemia [280.1, 280.8, 280.91	Age O-5 only, and examine principal and secondary diagnoses separately
Nutritional deficiencies [260, 261, 262, 268.0, 268. 1]	Examine principal and secondary diagnoses separately
Failure to thrive [783.4]	Age <1 only
Pelvic inflammatory disease [614]	Women only denominator - exclude cases with a surgical procedure of hysterectomy [68.3-68.8]
Dental conditions [521, 522, 523, 525, 528]	

List of conditions supplied by conference participant John Billings of New York University

Appendix A:

Conference Participants

Consensus Conference of Health Status Gaps of Low-Income and Minority Populations

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